

2011 Missouri Traumatic Brain Injury Needs Assessment Executive Summary



Institute for Human Development
A University Center for Excellence in Developmental Disabilities (UCEDD)

*A collaborative project of the Missouri Department of Health and Senior Services
and the University of Missouri Kansas City-Institute for Human Development.*

Executive Summary

The 2011 needs assessment was conducted by the Missouri Traumatic Brain Injury (TBI) Implementation Partnership Project, which is supported through a grant from the U.S. Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau. The purpose of the needs assessment is to help determine the needs of TBI survivors and their families in Missouri and to guide the state's five-year planning process.

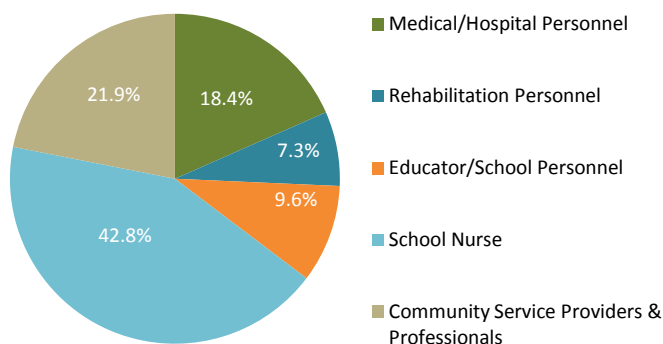
To support the assessment, two surveys were widely disseminated across Missouri. One survey targeted survivors and families, and one targeted professionals who serve people with TBI. (See full report for methodology and distribution.) Together, these surveys paint a picture of the current system of care, including gaps in service, quality of service, and the training needs of professionals.

Survey Participants

Survivors and Families: A total of 263 surveys were received - 134 from survivors, 110 from family, 6 from friends or other relatives, and 13 who did not identify themselves. Among the individuals with TBI, 31 (11.8%) identified themselves as former military, 20 (7.6%) lived in nursing facilities, 166 (63%) resided in urban counties, and 70 (26.6%) were from rural counties (not all respondents provided a zip code). Most of the participants (86%) were white, 6% were black, and other ethnic and racial populations represented less than 2% each. The majority of survivors (219) were aged 21-64, 15 were over the age of 65, and 20 were youth and children.

Professionals: There were 629 professional surveys received, from a variety of fields and professions, as shown in Figure E-1.

Figure E-1. Affiliation of Professionals Surveyed

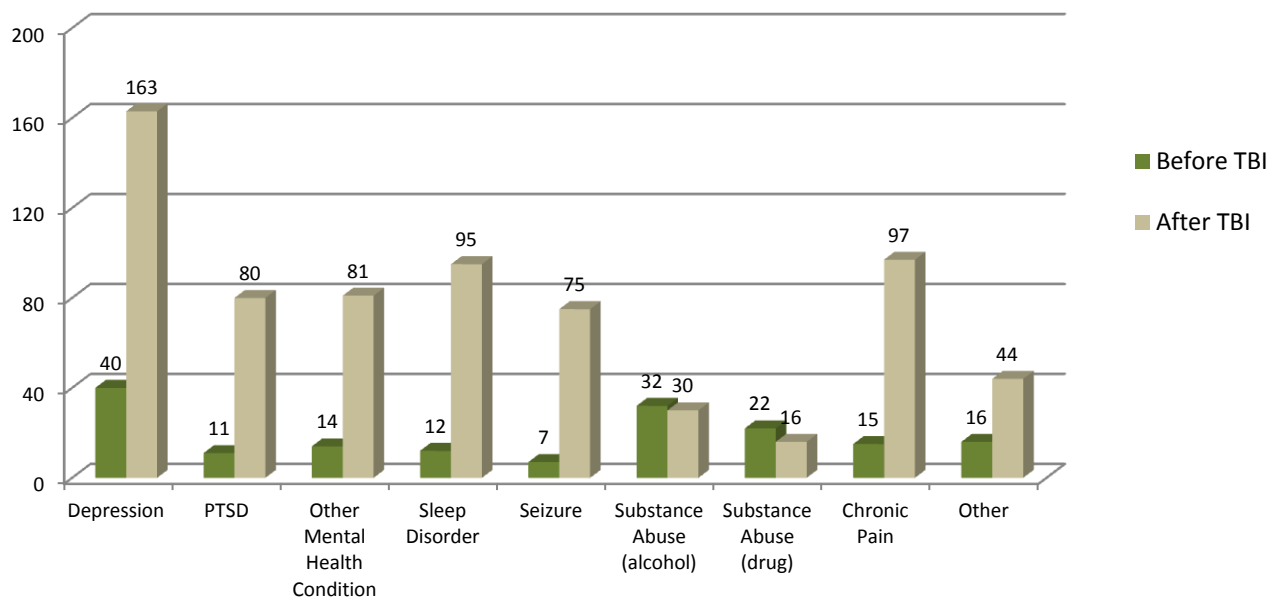


Impact of TBI on the Lives of Survivors and Families

To paint the most detailed picture of the needs of both TBI survivors and their families, the survey began by asking both groups to rate the impact of TBI on their lives in a number of key areas.

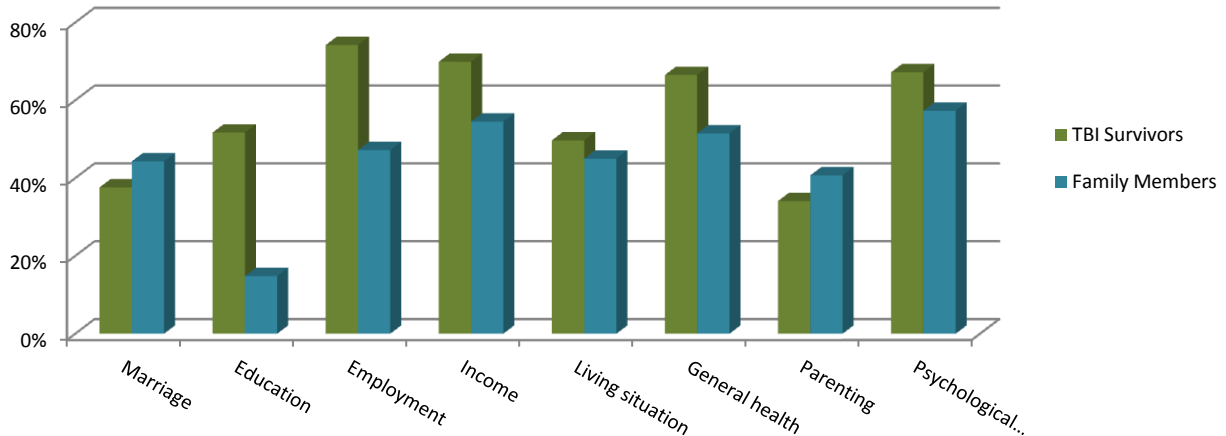
Figure E-2 compares the total number of health conditions before and after TBI. All the health conditions described in the graph show a two- to threefold increase post-TBI, with the exception of substance abuse (alcohol and drug), which decreased after TBI.

Figure E-2. Disabilities/Significant Health Conditions (n=246)



Respondents were also asked about the impact the TBI had on various aspects of their lives. Figure E-3 compares the survivors' perceptions of negative impact with the family members' perceptions. Survivors were more likely to say that education, employment and income were negatively affected, while more family members said that marriage and parenting were negatively affected.

Figure E-3. Negative Impact as Perceived by Survivors and Family



In order to identify the areas of greatest need, the surveys focused on three main topics:

- **The Continuum of Care:** The needs and experiences of both survivors and their families, from the first medical care received after the TBI to ongoing community services and supports.
- **People Living in Nursing Homes:** The needs of people with TBI living in nursing facilities, including why they moved there, whether they would like to leave, and barriers to leaving.
- **Professionals and the Public:** The training, information and resource needs of professionals, community groups, and the public.

For each topic, a series of questions was designed to gather both quantitative and qualitative data about the experiences, needs, and perceptions of the respondents.

Continuum of Care

To serve the unique needs of each individual living with TBI, Missouri must offer a continuum of care (hospital to community) with many entry points and many possible paths. This continuum of care includes:

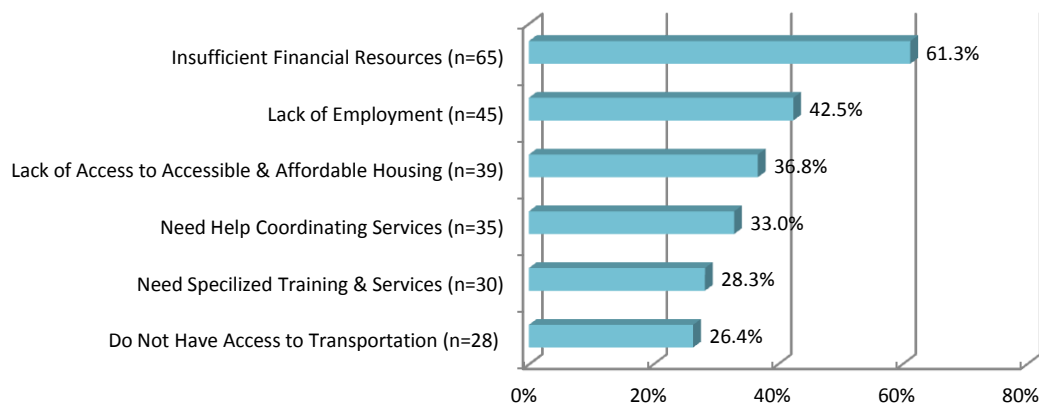
- Medical and Hospital Services (e.g., Emergency Room, Doctors Office, Hospital)
- Acute Rehabilitation Services (e.g., Inpatient/Outpatient Rehabilitation, Home Health Services)
- Community Services (e.g., Housing, Employment, Recreation, Counseling)

The surveys indicated that the continuum of care in Missouri is affected by lack of funding for services, lack of TBI training for professionals, lack of an easy way to learn about and connect to all available services, and scarcity of certain services, especially in rural areas. A brief summary of responses illustrates these challenges.

Living Situation

Gaps in the continuum of care often mean that survivors are not able to live where they would like to live. Among the survey respondents, 40% are not living where they want to. Asked where they want to live, the clear preference for most is to live on their own, with or without assistance (83%). Figure E-4 shows the interrelated factors of money and employment are the greatest barriers to moving. There is also a clear need for housing, service coordination, and specialized supports, which are issues that emerge consistently throughout the survey.

Figure E-4. Top Reasons People with TBI are not Living Where They Want



TBI Survivors in Nursing Homes

The 20 survey respondents who were living in nursing homes answered specific questions about their living situation and needs. Overwhelmingly they expressed a desire to move back to the community.

- 90% of TBI survivors in nursing homes wish to return to the community
- 75% entered the nursing home because they couldn't get the rehab services or medical care they needed at home
- 55% cited lack of financial resources and 35% cited lack of a job as reasons they can't leave the nursing home
- 12 nursing home residents were in rural areas, 7 in urban areas, and 1 unknown

Access to Care along the Continuum

It is clear that access to care changes as people move through the continuum from initial medical care to community supports and services. In both surveys and especially in the write-in comments, people repeatedly said that while acute care and rehabilitation were excellent, survivors and families returned home feeling extremely unprepared and not knowing where to turn for help. This was a matter of needing specific services as well as needing to find and connect with other survivors and families. Professionals were also asked to compare current services to those existing five years ago; across all categories there were small gains in the ratings (see full report). A look at responses in each service category helps to clarify the needs.

Medical and Hospital Care

These services were rated highest by both survivor/family and professional respondents. The average satisfaction for medical care on a 4-point scale was 3.16, compared to 3.03 for acute rehab and 2.68 for community services.

However, the write-in comments suggest that while survivors and families were largely satisfied with the quality of medical care received, they felt that communication with doctors and nurses was inadequate. Many people wrote of leaving the hospital with no understanding of how their lives would change and where to find services that might help. Similarly, when family members and survivors were asked which professionals needed to learn more about TBI, doctors and nurses were among the most frequently chosen (see full report for details on which professionals need to learn more).

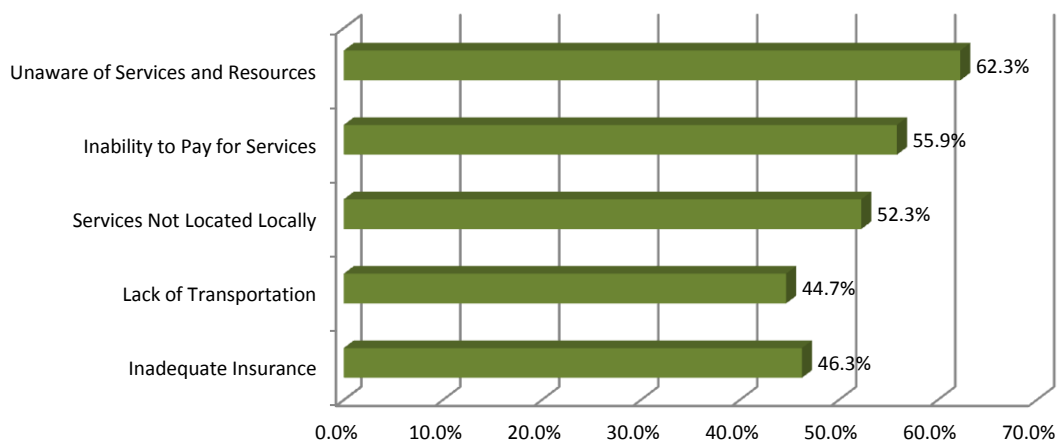
Acute Rehabilitation (inpatient, home health, outpatient)

Within this category, home health (nursing or therapy) was rated lower than inpatient or outpatient rehabilitation. Survivors and families also said home health was the rehabilitation service they most often needed but did not receive (20.8%). Professionals as well as survivors/families raised the issue of limited insurance coverage for rehabilitation therapy. As one survivor wrote, *“Therapy should be provided due to the person’s health and not the insurance company’s rules!”*

Community Services

In both the survivor/family and professional surveys, community services were rated the lowest, reflecting the greater complexity of navigating this system. To get a full picture of needs related to community services, it is useful to consider these responses together with the data from the “problems accessing services” question and the write-in comments (See Figure E-5).

**Figure E-5. Barriers to Service
Perceived by Survivors, Families, and Professionals**



“Unaware of Services” was the greatest barrier to services from the viewpoint of both professionals and survivor/family respondents.

The military subset reported far fewer problems with insurance and paying for services than the total respondent group, while rural respondents were more likely to say services were not located locally and insurance didn’t cover needed services.

Among services most often “needed but not received,” recreation services were most often reported (36.2%), followed by information and referral (32.3%) and continuing education related to TBI (30%). Assistance with financial management was needed but not received by 26.4% of respondents, and TBI support groups by 25.9%.

Services needed but not received and barriers to services clearly overlap in a few key areas:

Information: The high need for both “information and referral” and “continuing education about TBI” is consistent with “unaware of services and resources” as a barrier to services. This is reinforced in the write-in comments, where a large number of people mentioned the difficulty of finding information

about services and supports. In addition, both professionals and survivors/families identified service coordination as an important but underfunded resource for families struggling to understand the service system.

Finances: Personal finances, insurance coverage and eligibility for benefits are clearly interrelated and show up consistently as top concerns across all sections of the survey. The write-in comments shed further light on the problem: 51 survivor/family comments identified paying for services as a concern. People went without necessary services because they were denied Medicare or Medicaid coverage, their private insurance did not cover services, or they lost income due to the TBI.

Services not located locally: This was the biggest problem for rural respondents (54.9% vs. 27.8% of urban respondents). Among the top six services needed but not received, rural respondents especially identified TBI support groups and continuing education. The other major differences between rural and urban areas were service coordination (18.5% rural, 11.5% urban) and community living skills training (32.3% rural, 22% urban). The only services for which urban areas reported greater unmet needs were housing and information & referral.

Needs of Professionals and the Public

Professionals: Survivors and families were asked which professionals needed more training and what kind of knowledge and training they needed. Professionals were asked to rate their own knowledge about TBI services and supports and to report any TBI training they had received. Both surveys indicate a need for more training and information for professionals at all levels.

In comparing the two surveys, some interesting correlations emerge:

- Seventy percent of survivors and family members have met professionals who need to learn more about TBI, and 60% of professionals rated themselves as having “no knowledge” to “minimal knowledge” about service and supports for people with TBI.
- Professionals cited by survivors/families as needing to learn more about TBI tended to be the same ones who received the least TBI training as part of their professional education (medical, education, social work, and law enforcement personnel).

“The biggest challenge is trying to get ALL the players at one table that offer services for TBI, so we are all on the same page for referral and we know all of the services each of us has to offer”
TBI Professional

Adult Brain Injury Program providers (86.0%) and rehabilitation and therapy professionals (78.8%) had the highest percentages who received TBI training as part of their professional education.

Unsurprisingly, these groups were also more likely to rate their TBI knowledge as “moderate” to “a great deal.” Groups with higher knowledge tended to receive training from their organization, while groups with less knowledge tended to access TBI training from external sources.

General Public: Education efforts for the public were seen as an area that has improved; comments from both surveys mentioned the sports concussion media campaign as well as a general increase in public awareness about prevention and treatment of TBI.

However, survivor/family respondents and professionals saw a great need to provide more information to families about TBI and available community resources that are available. Survivors and families also stressed the need to educate the public to promote acceptance and inclusion of people with TBI in workplaces, schools, social settings and housing.

Summary Statement

Overall, TBI survivors and family members, like professionals, felt strongly that access to information, education and services needs to be improved. This includes information about the range of services that may be necessary, but just as importantly, it includes emotional/peer support for both family members and survivors. One survivor recommended “survivor outreach for new TBIs to assist and answer questions...and represent hope.” Another described TBI as a “very isolating injury.” It is clear that gaps in the continuum of care contribute to the isolation and frustration experienced by many, as well as impacting outcomes for survivors. But the data also provides direction about what works to alleviate and prevent these problems.

Respondents identified inadequate funding as a barrier to receiving both information and services. The need for accurate diagnosis and timely information about follow-up services is also clear, as is the need for the employment, transportation, housing, recreation, and other services that can allow TBI survivors to live in the setting of their choice and enjoy greater quality of life. A continuum of care that addresses the unique and changing needs of each person living with TBI must be both flexible and comprehensive; as one survivor put it, “No two TBIs are the same. Be creative and work with us in whatever aspect we need.”

Acknowledgements

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This effort was guided by the Needs Assessment Workgroup, established by the Missouri Brain Injury Advisory Council. Workgroup members included:

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